

# Influential factors of spousal relationship quality in couples living with dementia – A narrative synthesis systematic review

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## Abstract

**Aim:** The aim of this systematic review is to identify factors that influence relationship quality in couples living with dementia. Previous research has shown how maintaining a positive spousal relationship quality is important for quality of life and coping for both the caregiver and the person with dementia. Knowledge of influential factors could contribute to a deeper understanding of the value of a couple-centred clinical practice and research, within the field of dementia.

**Research design and methods:** Systematic procedures to database search, screening, data extraction and synthesis were followed. Qualitative, quantitative and mixed methods studies were included. A narrative synthesis was conducted through narrative summaries of included studies, thematic analysis and narrative descriptions of factors influencing relationship quality.

**Results:** 39 studies were included in the study: 28 qualitative, 8 quantitative and 3 mixed methods. Through the narrative synthesis, 20 factors were identified. The factors were grouped into two overarching themes: *The world of us* and *The world outside of us*, and further to six influencing factor categories: (1) *Attitudes and strategies*, (2) *Behaviour and activities*, (3) *Emotional connectedness*, (4) *Activities and experiences outside of the home*, (5) *Social behaviour and roles*, and (6) *Belonging and safety*.

**Discussion and conclusion:** The identified factors influence relationship quality in couples living with dementia on various levels. The findings of this review study should inform clinical, couple-centred dementia care practise and intervention studies, and further research should seek to gain deeper understandings of the individual factors and broader understandings of the correlations between factors.

## Keywords

relationship quality, couples living with dementia, couplehood, systematic review, narrative synthesis

## Introduction

Living with dementia influences the lives of both the person with a dementia diagnosis, and their family and friends. Dementia can give rise to social withdrawal, inappropriate or ambiguous vocal or bodily expressions, or increased dependence upon a partner or other caregivers, which in turn may influence the social relationships of the person with dementia (Feast et al., 2016). More than 50 000 000 people are living with dementia worldwide (World Health Organization, 2021). As 50% of people living with dementia are living at home (Alzheimer's Research UK, 2014), and approximately 40% live with their spouse or partner, it is estimated that there are at least 10 million couples living with dementia at home.

Although communication can be challenging, sustaining relationships, especially with close, significant others such as a spouse, is crucial for well-being for both the person with dementia and their spouse (Boss, 2011; Eriksen et al., 2016; Kitwood & Brooker, 2019a, 2019b; Power, 2016; Wray, 2020). Research on dementia and spousal relationships tends to focus on the caregiver burden of the spouse (Adelman et al., 2014; Etters et al., 2008; Evans & Lee, 2014). However, positive aspects of caregiving are also investigated in an increasing number of studies (Abdollahpour et al., 2018; Fauth et al., 2012; McLennon, 2008; Riley et al., 2020; Riley et al., 2018). While the concept of *personhood* is well established within multidisciplinary practice and research (Hydén et al., 2014; Kitwood & Brooker, 2019a, 2019b), the term *couplehood* is suggested as a broadening of the perspective, from a focus on the person with dementia as an individual or subject to an intersubjective focus (Hellström, 2014; Kaplan, 2001). This narrative

synthesis aims to contribute to an insight of the lived couplehood of persons with dementia and their spouses.

To maintain positive, close relationships can be a significant factor for experiencing meaning in life for persons with dementia (Dewitte et al., 2021). Hellström and Torres (2021) found that some spousal partners view the experience of living with a partner with dementia from a we-perspective or “couple-centred approach” and describe both challenges and joys as something that is shared between the two as partners. Partners with a couple-centred approach seem to cope better with caregiver burden than those with a me-perspective or what the authors call an “egocentric approach”, who tend to focus on their subjective, individual experience with dementia as separated from their partner’s experiences and challenges.

Relationship quality between people with dementia and their family caregivers is frequently discussed in the research literature, although influential factors may not be the main focus of the studies. Two published systematic reviews present influential factors on relationship quality in spousal couples and other family relationships in the context of dementia care (Ablitt et al., 2009; Conway et al., 2018). One ethnographic meta-analysis of qualitative research, review how couples share experiences of dementia (Wadham et al., 2016). These three reviews all argue for the need for a couple-centred focus in dementia care services and interventions: to keep a dyadic perspective and sense of couplehood seems to enhance quality of life, everyday coping, and resilience for both the person with dementia and their partner. However, practitioners and researchers still need knowledge of factors that may influence relationship quality negatively and positively, to be able to design and deliver relevant couple-centred services and interventions. Therefore, the purpose of this narrative synthesis systematic review is to identify significant factors that impact relationship quality in spousal couples living with dementia (hereafter called relationship quality), to inform further couple-centred dementia care practice and research within multiple fields.

The review aims to answer the question *What factors influence spousal relationship quality in couples living with dementia?*

There are several possible definitions of the term relationship quality, and there seems to be no consistent definition used in the existing literature. For the purpose of this review, the following definition is used: The couple’s own feeling or perception of the degree to which their relationship is healthy, balanced, enjoyable, intimate, and/or fulfilling for them individually and/or as one unit. This definition is a synthesis of possible definitions we consider relevant for this study, and it guided the protocol, which was registered in PROSPERO October 29th, 2019 (Registration ID CRD42020211667)

## Methods

### Search strategy

Searches were conducted in five databases: PubMed, PsychInfo, Cinahl, Music Periodicals and SveMed+. The first three were included to cover the broad spectrum of research in health, medicine, nursing and psychology, including family therapy. Music Periodicals Database was included to locate any music therapy or other arts therapies research not represented in other databases, and SveMed+ to identify relevant research published in Scandinavian languages.

Searches were conducted on 18<sup>th</sup> and 19<sup>th</sup> of May 2020, with follow-up searches 29<sup>th</sup> of January 2021, and 14<sup>th</sup> of January 2022. The follow-up searches were identical to the original search, and in line with the registered protocol. Databases were searched with the keywords *dement\** OR

alzheimer\* OR elderly OR elder\* AND spous\* OR couple\* OR couplehood OR life partner AND relation\* OR intimate OR intimacy OR closeness OR we-ness.

### *Eligibility criteria and screening process*

This review included qualitative, quantitative and mixed methods research published in peer-reviewed journals, between the years 1995 and 2022. The limit of 1995 was set due to the major shift in dementia caregiving research in the early 1990s; from the bio-psychiatric model of understanding persons with dementia, to the biopsychosocial model, often referred to as the person-centred model (Kitwood & Brooker, 2019a, 2019b). Research published in other languages than English or Scandinavian languages were excluded in the title screening, as well as theses, books and reports.

The further inclusion criteria were:

- o Research focusing on spousal relationships
- o Research focusing on persons with dementia of all ages, and their spouses of all ages, living in their home
- o Research focusing on influences or influential factors on relationship quality

Studies focusing exclusively on the dementia diagnosis or diagnostic assessment scale scores as the only described influence on relationship quality, were excluded, leaving studies focusing on psychosocial factors such as strategies or behaviours, activities and interventions for inclusion.

All titles were imported to Rayyan, a web-based systematic review software application (Ouzzani et al., 2016). All titles were screened by two authors (KS, n = 3123, FB, n = 1562, TK, n = 1562), according to inclusion criteria. This process was masked, revealing agreements and conflicts regarding inclusion/exclusion. The conflicts were further assessed by the three authors as a group, where a final decision of inclusion or exclusion was made.

### *Quality appraisal*

The CASP quality appraisal tools (Critical Appraisal Skills Programme, 2018) were used, and studies were classified as of either strong, moderate or weak in quality. Studies classified as “weak” by both assessing authors, were assessed by a third author to consider whether the quality was too weak for inclusion for data extraction and synthesis.

### *Data extraction and narrative synthesis*

Data extraction (see appendix 1 for an example of the initial data extraction) and synthesis were completed by the first author (KS), with three co-authors (FB, TK, H O-M) reviewing the process at several time-points to ensure trustworthiness of the analysis and synthesis. The narrative synthesis was completed guided by Popay et al.’s (2006) four steps of narrative synthesis.

*Step 1. Narrative summaries.* Short, textual descriptions (summaries) of the results and discussion of each of the included studies were written. Relevant direct quotes describing influences on relationship quality in couples living with dementia were included in the descriptions. See appendix 2 for example of narrative summary.

*Step 2. Coding for developing themes.* Key words, sentences and results from the narrative summaries were coded using the Thomas and Harden framework for thematic synthesis in systematic reviews (Thomas & Harden, 2008). This included an open coding of text, using the

summaries to identify themes. The NVivo software program for qualitative data analysis was used for this process, for robustness and a systematic inductive coding (Elliott-Mainwaring, 2021). The original articles were cross checked for direct reference to the studies, both to ensure sufficient rigour in the synthesis and to extract examples and quotes illustrating the themes. See appendix 3 for a list of the initial codes.

*Step 3. Grouping of themes into categories.* The list of codes was arranged, rearranged and grouped into overarching themes, main categories and subcategories. Similarities and differences between the themes were explored and where necessary, themes were collapsed into larger themes or split into more distinct themes. All main categories and subcategories can be linked directly through quotations to the results of the original, included studies.

*Step 4. Narrative descriptions of factors.* A narrative description of each of the identified influential factors was written with reference to influence categories and links to the original articles through quotations. The narrative descriptions are individual yet connected stories of factors influencing relationship quality for spousal couples living with dementia. Modified versions of the narrative descriptions are presented in the results section.

## Results

### Article selection

The search in the five databases resulted in 5955 texts in total. Reference check of the included studies led to the inclusion of two additional studies. The total number of included studies after screening and quality appraisal was 39. Figure 1, based on the PRISMA flow diagram (Page et al., 2021), shows the screening process in detail.

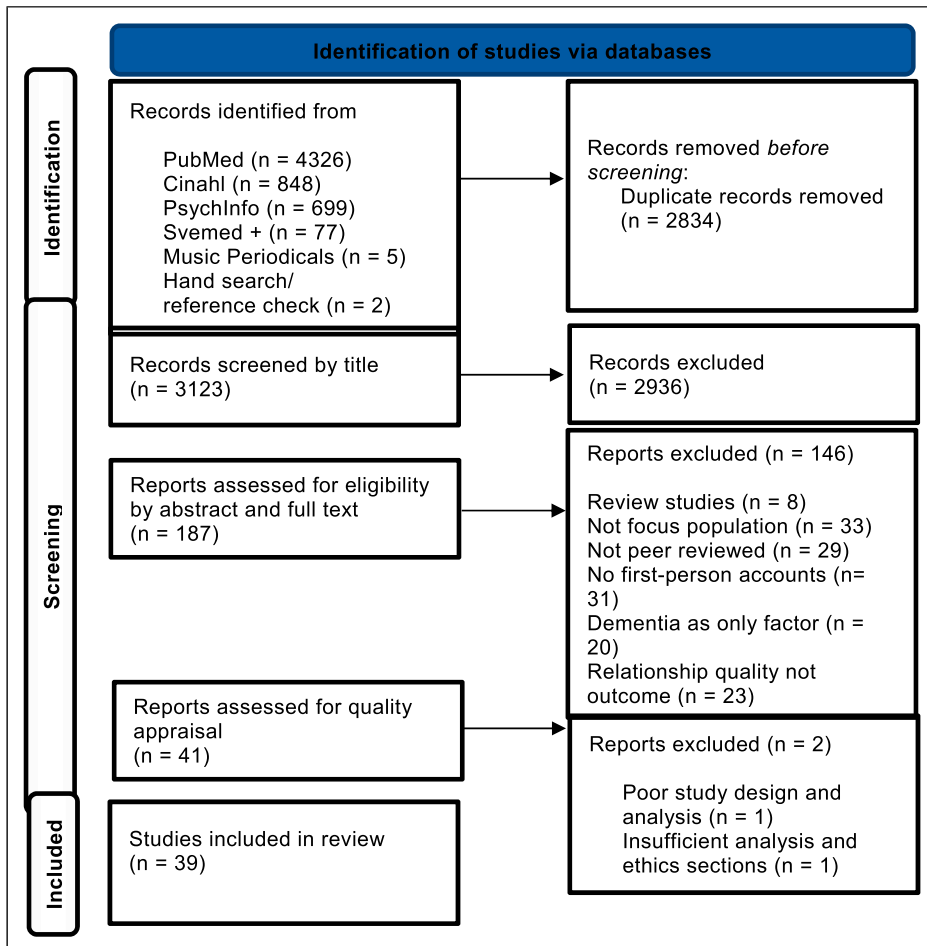
### Extraction of findings and results from the studies

The included studies comprised 28 qualitative, 8 quantitative, and 3 mixed methods studies with the majority of studies conducted in Western, developed countries. The numbers of participants/sample sizes varied greatly, from two persons (single case study of a couple with dementia) to 356 persons. 21 of 39 included studies involve persons with dementia directly through interviews or conversations. A multitude of study designs and methods was also evident with qualitative studies dominated by grounded theory or phenomenology. Table 1 shows a tabulation of the nationality, populations, sample sizes, diagnoses, interventions and study designs of each study.

### Results from the narrative synthesis

*Overarching themes: The world of us, and the world outside of us.* Twenty factors that influence relationship quality were identified, and these were grouped into six influence categories. Three of the categories have been grouped to the overarching theme: *The world of us*, as the factors in these categories occur within the dyadic world of the couple. Further, three influence categories were grouped to: *The world outside of us*, as these categories describe social factors that include family, friendship or community settings. Table 2 provides an overview of the overarching themes, influence categories and factors. The table also gives direct reference to the original articles that describe the factors. The references in bold font show studies concerning that specific factor in particular.

In the following, each factor is described. These descriptions are based on step 4 of the narrative synthesis: *Narrative descriptions of factors*. The narrative descriptions have been shortened, and



**Figure 1.** (diagram based on PRISMA flow diagram (Page et al., 2021)).

quotes from original articles have been added. The quotes are cited verbatim from the original texts, including formatting, brackets and other characters.

### *Overarching theme 1: The world of us*

*Influence category 1: Attitudes and strategies. Factor 1: Adaption to loss.* To live with dementia often leads to a feeling of loss, and frustration for both individuals in the relationship. This may lead to a disruption to the quality of the relationship. Partners may experience feelings of helplessness and resentment towards their spouse with dementia. When couples share an attitude of facing the challenges of dementia together, through acceptance of the other, adaptation of one's own patterns and reactions, and being open with each other, they may help themselves and each other with coping with the feeling of loss.

Table 1. ■■■.

Study	Nationality	Population/ diagnoses/living situation	Sample size	Intervention	Study design
Allan, 2018	New Zealand	CWD (DU), home	3 CWD (n = 6)	Group music therapy	Mixed methods
Baker et al., 2012	Australia	CWD (DU), home	5 CWD (n = 10)	Home-based music therapy programme	Concurrent triangulation design
Balfour, 2014	UK	CWD (DU), home	1 CWD (n = 2)	Couples therapy programme	Case description
Bauer et al., 2001	USA	CWD (AD), home	115 CWD (n = 230)	None	Exploratory
Bielsten et al., 2018	UK/Sweden	CWD (AD), home	5 CWD (n = 10)	None	Explorative deductive-inductive 3-phase
Botsford et al., 2012	UK	Partners (DU), unspecified living situation	13 partners (n = 13)	None	Interview study, grounded theory
Boylstein & Hayes, 2012	USA	Partners (AD), home	28 partners (n = 28)	None	Interview study, grounded theory
Bruinsma et al., 2020	The Netherlands	CWD (YOD), home	178 CWD (n = 356)	None	Longitudinal 2-year cohort study
Clare et al., 2012	UK	CWD (DU), home	104 CWD (n = 208)	None	Longitudinal cross- section with control
Clark et al., 2019	UK	CWD (DU), home	6 CWD (n = 12)	None	Interview study, IPA
Colquhoun et al., 2019	UK	CWD (DU), home	10 CWD (n = 20)	None	Interview study, grounded theory
Daley et al., 2017	USA	CWD (AD), home and inst.	11 CWD (n = 22)	None	Comparative study
Daniels et al., 2007	USA	CWD (AD), home	1 CWD (n = 2)	None	Single-case interview study
Davies et al., 2010	USA	Partners (MCI), home	23 partners (n = 23)	None	Focus group interview study
Davies, 2011	Canada	CWD (AD), home	6 CWD (n = 12)	None	Mixed methods
DeVugt et al., 2003	The Netherlands	CWD (DU), home	53 CWD (n = 106)	None	Regression analysis
Gallagher & Beard, 2020	USA	CWD (AD), home	11 CWD (n = 22)	None	Interview study, grounded theory
Garand et al., 2007	USA	Partners (MCI), home	27 partners (n = 27)	None	Cross-sectional, descriptive, correlational design

(continued)

Table 1. (continued)

Study	Nationality	Population/ diagnoses/living situation	Sample size	Intervention	Study design
Harris, 2009	USA	CWD (MCI), home	16 CWD (n = 32)	None	Interview study, grounded theory
Hellström et al., 2005	Sweden/UK	CWD (AD), home	1 CWD (n = 2)	None	Single case interview study
Hellström et al., 2007	Sweden/UK	CWD (DU), home	20 CWD (n = 40)	None	Interview study, grounded theory
Hickman et al., 2020	UK	CWD (DU), home	10 CWD (n = 20)	None	Interview study, IPA
Ingersoll- Dayton et al., 2013	USA	CWD (DU), home and inst.	24 CWD (n = 48)	Couples life story programme	Feasibility study
Merrick et al., 2016	UK	CWD (DU), home	7 CWD (n = 14)	None	Interview study, IPA
Molyneaux et al., 2012	UK	CWD (AD), home	5 CWD (n = 10)	None	Interview study, grounded theory
Nilsson & Olaison, 2019	Sweden	CWD (DU), home	15 CWD (n = 30)	None	Interview study, conversation analysis
O'Shaughnessy et al., 2010	UK	Partners (DU), home	7 partners (n = 7)	None	Interview study, IPA
Roberto et al., 1998	USA	CWD (AD), home	14 CWD (n = 28)	None	Case study, questionnaire
Robinson et al., 2005	UK	CWD (AD and VD)	9 CWD (n = 18)	None	Interview study, IPA
Sanders & Power, 2009	USA	Partners (DU), home	17 partners (n = 17)	None	Interview study, phenomenology
Searson, 2008	UK	CWD (DU), home	46 CWD (n = 92)	None	Cross-sectional two- site study
Shavit et al., 2019	Israel	Partners (AD), home	16 partners (n = 16)	None	Interview study, thematic analysis
Sherman & Boss, 2007	USA	Partners (DU), home	9 partners (n = 9)	None	Interview study, grounded theory
Simonelli et al., 2008	Italy	Partners (AD), home	200 partners (n = 200)	None	Comparative clinical control design
Stefansdottir et al., 2021	Iceland/ Norway	Partners (DU), home	8 (n = 8)	None	Qualitative, constructivist grounded theory study
Swall et al., 2020	Sweden/USA	CWD (DU), home	15 CWD (n = 30)	None	Conversation analysis

(continued)



**Table 1.** (continued)

Study	Nationality	Population/ diagnoses/living situation	Sample size	Intervention	Study design
Vikström et al., 2008	Sweden	CWD (DU), home	26 CWD (n = 52)	None	Interview study, comparative analysis
Williams, 2015	USA	CWD (AD), home	15 CWD (n = 30)	None	Conversation analysis
Youell et al., 2015	UK	Partners (DU), home	6 (n = 6)	None	Interview study, IPA

CWD = couples with dementia; DU = diagnosis unspecified; AD = Alzheimer's Disease; YOD = young onset dementia; MCI = mild cognitive impairment; VD = vascular dementia.

'You adjust to it, I mean the abnormal has become normal (laughing) as you might say'. [Wife with dementia] (Robinson et al., 2005, p. 342)

*Factor 2: Coping and adjustment to the new situation.* Participants in several studies reported that taking 1 day or one moment at a time was a coping strategy for them. The synthesis indicated that actively sharing their common history through reminiscing and collaborative story-telling supported relationship quality.

People say to me 'how on earth do you cope?' People say to me 'you cope so well'. I don't know whether I sort of push it down, and. . . try not to think of what is coming, the future. . . . And trying hard not to look too much at what happened in the past. And just cope with day-to-day things and not look too far ahead. That's one thing I definitely try not to do. Is not look far ahead I know what's coming, but. . . um I try to adapt. . . as it goes along. . . (O'Shaughnessey et al., 2010, p. 251)

*Factor 3: Feelings and attitudes of commitment.* The synthesis revealed that when couples shared a feeling of commitment, of being *partners for life*, this promotes resilience during challenging periods. Though living with dementia leads to feelings of loneliness for both members of the couple, the attitude of staying true to their commitment brings meaning to the relationship.

I married Mark, in sickness and in health and now he's really sick, but it's for life. (Sue) (Merrick et al., 2016, p. 39)

*Factor 4: Feelings and attitudes of reciprocity/mutual respect.* This factor is often related to the habits and patterns from the history of the couple, according to the included studies. Couples who express that respect and reciprocity has been central in their life together, often also report a high relationship quality when they live with dementia.

Reciprocity, or the 'give and take' in each couple's marital relationship, was present despite one spouse's dementia. Shared meaning was still experienced by both spouses, although relations of equal reciprocity

Table 2. ■■■.

Influence categories	Factors	Reference texts
THEME 1. The world of us		
Influence category 1: Attitudes and strategies	1. Adaption to loss	Bielsten et al. (2018), Boylstein and Hayes (2012), Clark et al. (2019), Colquhoun et al. (2019), Davies et al. (2010), Merrick et al. (2016), Robinson et al. (2005), Swall et al. (2020), Simonelli et al. (2008)
	2. Coping and adjustment to the new situation	Bielsten et al. (2018), Boylstein and Hayes (2012), Clark et al. (2019), Colquhoun et al. (2019), Daniels et al. (2007), Davies et al. (2010), Gallagher and Beard (2020), Harris (2009), Hellström et al. (2005, 2007), Merrick et al. (2016), O'Shaughnessy et al., 2010, Robinson et al. (2005), Swall et al. (2020)
	3. Feelings and attitudes of commitment	Davies (2011), Harris (2009), Merrick et al. (2016), O'Shaughnessy et al., 2010, Shavit et al. (2019), Swall et al. (2020), Daley et al. (2017)
	4. Feelings and attitudes of reciprocity/mutual respect	Davies (2011), Gallagher and Beard (2020), Shavit et al. (2019)
	5. Humour and playfulness	Boylstein and Hayes (2012), Harris (2009), Hickman et al. (2020), Allan (2018), Baker et al. (2012)
Influence category 2: Behaviour and activities	6. Behavioural and psychological symptoms of dementia	Boylstein and Hayes (2012), Davies et al. (2010), Sanders and Power (2009), Bauer et al. (2001), Bruinsma et al. (2020), Clare et al. (2012), DeVugt et al. (2003), Garand et al. (2007), Simonelli et al. (2008), Stefánsdóttir et al., 2021
	7. Communication patterns	Boylstein and Hayes (2012), Bruinsma et al. (2020), Davies et al. (2010), Hellström et al. (2007), O'Shaughnessy et al., 2010, Roberto et al. (1998), Shavit et al., 2019, Williams (2015)
	8. Shared activities and sustaining common interests	Bielsten et al. (2018), Boylstein and Hayes (2012), Gallagher and Beard (2020), Gallagher and Beard (2020), Hellström et al. (2005), Vikström et al. (2008), Allan (2018), Baker et al. (2012), Bauer et al. (2001), Searson (2008)
	9. Attending couples counselling and music therapy programs	Auclair et al. (2009), Balfour (2014), Ingersoll-Dayton et al. (2013), Allan (2018), Baker et al. (2012)

(continued)

**Table 2.** (continued)

Influence categories	Factors	Reference texts
Influence category 3: Emotional connectedness	10. Love	Bielsten et al. (2018), Boylstein and Hayes (2012), Clark et al. (2019), Colquhoun et al. (2019), Davies et al. (2010), Gallagher and Beard (2020), Harris (2009), Merrick et al. (2016), Sanders and Power (2009), Shavit et al. (2019), Swall et al. (2020)
	11. Sexual intimacy	Bielsten et al., (2018) Youell et al. (2015)
	12. Sense of couplehood, we-ness, us-identity	Bielsten et al. (2018), Davies (2011), Gallagher and Beard (2020), Harris (2009), Hellström et al. (2005, 2007), Merrick et al. (2016), Molyneaux et al. (2012), Swall et al. (2020), Daley et al. (2017)
	13. Sharing of memories, feelings, and future plans	Bielsten et al. (2018), Daniels at al. (2007), Gallagher and Beard (2020), Ingersoll-Dayton et al. (2013), Merrick et al. (2016), Molyneaux et al. (2012), Nilsson and Olaison (2019), O'Shaughnessy et al., 2010, Swall et al. (2020), Williams (2015), Allan (2018), Baker et al. (2012)
	14. Experiences of changing roles	Boylstein and Hayes (2012), Davies et al. (2010), Harris (2009), Hellström et al. (2005), Merrick et al. (2016), Molyneaux et al. (2012), O'Shaughnessy et al., 2010, Sanders and Power (2009), Seaman (2020), Stefánsdóttir et al., 2021 Vikström et al. (2008)
THEME 2. The world outside of us		
Influence category 4: Activities and experiences outside the home	15. Self-managed leisure activities	Bielsten et al. (2018), Boylstein and Hayes (2012), Gallagher and Beard (2020), Sanders and Power (2009), Vikström et al. (2008)
	16. Organised activities and programs	Bielsten et al. (2018), Boylstein and Hayes (2012), Gallagher and Beard (2020), Harris (2009), Hellström et al. (2005), Vikström et al. (2008), Allan (2018), Baker et al. (2012)
Influence category 5: Social behaviours and roles	17. Reactions to dementia symptoms from the world outside	Botsford et al. (2012), Boylstein and Hayes (2012), Shavit et al. (2019), Vikström et al. (2008) Bauer et al. (2001)
	18. Changing roles within family and friendship contexts	Bielsten et al. (2018), Gallagher and Beard (2020), Sherman and Boss (2007),
Influence category 6: Belonging and safety	19. Belonging to a group	Bielsten et al. (2018), Boylstein and Hayes (2012), Daniels at al. (2007), Harris (2009), Hellström et al. (2005), Allan (2018)
	20. Safe and unsafe spaces outside the home	Bielsten et al. (2018), Daniels at al. (2007), Gallagher and Beard (2020), Hellström et al. (2005), Vikström et al. (2008), Allan (2018)

were difficult to attain as the spouse with dementia was no longer able to reciprocate equally. This didn't appear to be a problem. (Davies, 2011, p. 227)

*Factor 5: To maintain a sense of humour and a playful attitude* may offer a sense of coherence in the relationship, and it can increase positive emotions in the couple:

'It [humour]'s a release, it's breaking the frustration, the tension, the aggravation, the anger. . .' (Dave). (Hickman et al., 2020, p. 1805)

*Influence category 2: Behaviours and activities. Factor 6: Behavioural and psychological symptoms in the person with dementia.* Dementia related personality changes, communication breakdown, and lack of expressed interest and affection towards each other, negatively impacts relationship quality in couples. Narratives suggest that when the spouse with dementia displays more severe behavioural and psychological symptoms of dementia, depression and apathy, lower relationship quality is experienced when compared with couples whose behaviours are milder in severity (Bruinsma et al., 2020; DeVugt et al., 2003; Garand et al., 2007).

*Factor 7: Communication patterns.* Miscommunication and repeated questions are verbal communication patterns that may stress both members of the couple, thereby negatively influencing relationship quality. Couples where the healthy spouse expresses affection, avoids conflict triggers, poses direct questions, formulates short succinct messages, and allows space for the spouse with dementia to respond, experience less stress and a more positive communication. While communication challenges may lead to an unsatisfactory emotional and sexual relationship, partners who actively address the needs of their spouse with dementia, experience enhanced closeness and intimacy. Conversely, couples where the healthy spouse ignores their spouse's challenges and focuses on their own caregiver burden, report lower relationship quality and satisfaction.

Now, when I take the key, he starts swearing at me, starts cursing me, getting angry with me. "Where, where, where"... and I don't know what he wants. "Where, where, where." I say: "Take me by the hand, show me what you want." But there is no one to talk to, no one to talk to. (Shavit et al., 2019, p. 18)

*Factor 8: Shared activities and sustaining common interests.* Being able to do things together in a meaningful way for both and to keep an active lifestyle on the couples' own premise may enhance positive feelings.

Just being able to be together and enjoy and listen to something we love is a benefit. To share something is a good thing and this is still something we want to do and are able to do. ... we also came to enjoy spending this time together. [...] It was our common ground as such so we didn't need words. (Baker et al., 2012, p. 14)

*Factor 9: Attending couples' counselling and music therapy programs.* Four studies describe counselling or therapy programs which had a positive influence on the participating couples' relationship quality. This is shown through reports of enhanced closeness between the two. A shared life stories program enhanced intimacy and meaningful couple interaction (Ingersoll-Dayton et al., 2013), while two music therapy programs created a safe space for common engagement and connection (Allan, 2018), and strengthened reciprocity and overall relationship quality (Baker et al., 2012).

*Influence category 3: Emotional connectedness. Factor 10: Love.* The concept of “being in love” and “loving each other” is highlighted in several of the included articles. Studies suggest that love seems to be a central experience of how couples maintain a positive relationship quality. Terms such as “love”, “closeness”, and “maintaining a bond” permeated the data analysed.

Interviewer: Do you have a good time?

Wife: Yes, I really think so. We have a nice time together at home, and that is what we are saying every day. ‘Oh God, such a nice time we have, you and I’; ‘Yes’ says my husband ‘that is thanks to you’; ‘No’, I say, ‘it is thanks to you’. That’s how it is. (Hellström et al., 2007, p. 394)

*Factor 11: Sexual intimacy.* Experiences of physical and/or sexual intimacy may change within the couple as dementia progresses, thereby impacting relationship quality. Couples who are able to re-define intimacy to include activities and behaviours that transcend physical attraction and sex, may experience relational benefits. Conversely, sexuality and intimacy can challenge some couples when the two individuals’ sexual needs differ. When there are significant personality changes in the person with dementia, a healthy spouse may experience sexual intimacy as problematic suggesting it is like “[having] sex with a stranger” (Youell et al., 2015, p. 13).

*Factor 12: Sense of couplehood, we-ness, us-identity.* This concept is close to *Love* and *Closeness*. An important part of the sense of a “we” is safety: the experience of the relationship and the shared home as a “safe space”, as well as a feeling of closeness and enjoying to spend time together, moment by moment:

Woman looks at him saying: “Here we are spending good times together.” Man nodding and says: “yes, yes.” Woman looks at him saying: “Trying to live in the moment.” Man looks at the table nodding and says: “Right, right.” Woman looks at him saying: “Not in the past, not in the future, but only in the moment.” (Swall et al., 2020, p. 6)

*Factor 13: Sharing of memories, feelings, and future plans.* Such sharing includes reminiscing, the use of music or other activities to evoke memories, and being open to share feelings, dreams, fears and plans for the future.

[...] husband with memory loss read aloud the letter to his wife in which he had proposed to her. Afterwards he stated, “That probably is one of the best things I wrote.” His wife emphatically responded, “You are right” and then kissed him. (Ingersoll-Dayton et al., 2013, p. 9)

Memories and feelings can also negatively affect relationship quality. Shavit et al. (2019) describe couples with a turbulent past, in which living with dementia leads to further anger and resentment and a reluctance in the healthy spouse to provide necessary help for the spouse with dementia.

*Factor 14: Experiences of changing roles.* As the disease progresses, it is common for couples to experience role changes which may impact relationship quality. The most frequently reported role changes seems to be where the role of spouse transforms to be one of a caregiver, sometimes referred to as the spouse’s “nurse” or even “parent”. The change from spouse to care recipient, or patient, is also frequently described, however, almost exclusively from the healthy spouse’s perspective.

At my age, I don't really want to take care of a child. And I have to, and that's my frustration. And I know that will never change. I feel guilty about my thoughts and know that when she is gone I will regret every feeling of frustration I've had. (Sanders & Power, 2009, p. 49)

Role changes may lead to a poorer relationship quality because maintaining a sense of couplehood, closeness or intimacy is threatened when time, effort and energy is invested in caregiving. Conversely, the change in role of spouse to caregiver may also strengthen the healthy spouse's capacity to cope with the situation, and further a renewed and adjusted relationship quality.

## Overarching theme 2: The world outside of us

*Influence category 4: Activities and experiences outside the home. Factor 15: Self-managed leisure activities.* To engage in activities together, such as socialising with others, is a significant factor for maintaining a positive relationship. These activities include self-directed leisure activities that the couple have and continue to enjoy together, as well as organised groups or programs. Chosen self-managed activities should be based on the couple's preferences, needs and possibilities, and often include socialising with family and friends.

Mrs. Williams explained that she tailored activities so they would not be too difficult for her husband. Instead, she focuses on the activities that her husband could actively participate in, "I don't think he could play cards. I don't think he could play games. That would be befuddled in there. So I just would not do that. That's all. But he can play golf and keep his score and all that" (Mrs. Williams, spouse). (Gallagher & Beard, 2020, p. 5)

*Factor 16: Organised activities and programs.* This factor includes support groups, activity centres for persons with dementia and their caregivers, couples' conversation groups and group music therapy. Such activities may provide the facilitation, safety, and support couples living with dementia need and seek. Both activities directed towards people with dementia, and general activities, are described in the included literature.

It was amazing to see the participants come out of their shell as the weeks progressed and form bonds not only with each other but also reconnect with their loved ones through story and song. (Allan, 2018, p. 45)

*Influence category 5: Social behaviours and roles. Factor 17: Reaction to dementia symptoms from the world outside.* Behaviour changes in the spouse with dementia may negatively impact how the couple interacts when socialising with other people. Other people's negative reactions to inappropriate or unusual behaviour, or the fear of such reactions, may cause embarrassment in one or both spouses, leading to social withdrawal. One study suggests that diminishing social skills lead to a decrease in relationship quality, though without significant results (Bauer et al., 2001). Two studies argue that the fear of reactions, and embarrassment, in the healthy spouse can be a cultural issue (Botsford et al., 2012; Shavit et al., 2019).

And then like last night, he was out on the floor dancing and I mean some people would have thought he was drunk and making a fool out of himself and on one hand it's painful to see him, you know. It hurts me really bad to see him like that, kind of like making a spectacle of himself. (Boylstein & Hayes, 2012, p. 600)

*Factor 18: Changing roles within family and friendship contexts.* Family members or friends may not understand, or may feel uncomfortable with, the couple's role changes. A consequence can be decreased social contact with the couple and thus an increase in the couple's social isolation. This seems especially evident in late re-married couples, with children from earlier marriages (Sherman & Boss, 2007). In contrast, maintaining an already established role in social contexts can lead to increased self-esteem and social wellbeing for couples living with dementia.

"We've chosen to stop seeing a couple of friends. One was so overly helpful and wanted to "take care of" so much it became offensive. It's sad, but we have to socialize with people who make us feel good". (Bielsten et al., 2018, p. 20)

*Influence category 6: Belonging and safety. Factor 19: Belonging to a group.* For couples to feel they belong to a group or society, with a sense of being accepted of, and important to the others, may enhance the quality of the relationship. Social support received from others seems especially important to the healthy spouse, as social interaction may contribute to a hope for the future. Friends and family who help with practical tasks of daily living bring relief to the healthy spouse so they can invest time and energy to participate in positive activities. An active social life can lead to greater closeness and intimacy as the distinction between being with other people and being a couple alone reminds them of the importance of "us" (Harris, 2009).

In many respects 'doing things together', particularly with the church, provided the foundation for their relationship, and maintaining contact with the church was central to both Mrs and Mr Svensson's conceptions of 'who they are'. Indeed, for Mrs Svensson this was one of the things that she found most important in her life (Hellström et al., 2005, p. 16)

*Factor 20: Safe and unsafe spaces outside the home.* The feeling of being safe in the social arenas the couple frequents, influences the couple's social engagement. Arenas where other people are aware of the couple's situation, and share an inclusive attitude offer such safe spaces. If a social arena or group feels unsafe for one or both of them, it can cause distress and behavioural issues, with withdrawal and social isolation as a consequence for the couple.

## Discussion

This review aims to give answers to the research question: *What factors influence spousal relationship quality in couples living with dementia?* The narrative synthesis led to an identification of 20 factors. Within the dyadic perspective of the couple (overarching theme - *The world of us*), the influential factors were categorised as *Attitudes and strategies*, *Behaviour and activities*, and *Emotional connectedness*. Within a broader, social perspective (overarching theme - *The world outside of us*), factors were categorised as *Activities and experiences outside the home*, *Social behaviour and roles*, and *Belonging and safety*.

While earlier systematic reviews of relationship factors and dementia have included all informal caregiving relationships, the present study has focused exclusively on spousal relationships. This focus limits the possibility for a broader discussion of present findings in relation to earlier findings. Nonetheless, it offers possibilities for deeper understandings of factors like spousal closeness and intimacy. Ablitt et al. (2009) conclude that interaction between the two, the couple's shared history, and their shared experience of living with dementia may influence the relationship quality, all of which are confirmed and further elaborated on in the present study. Conway et al. (2018) show how

factors related specifically to the person with dementia, the caregiver, and to the two as one unit, has influence on the relationship quality. The present study has chosen the latter focus throughout, thus embedding the individual foci into the couplehood approach. While spousal intimacy and sexual closeness were absent and requested for further research by Conway et al., (2018), these aspects are included in the literature and analyses of the present study, showing to be a significant factor for relationship quality.

Some perspectives seem evident for several of the factors, offering opportunities for further theoretical and clinical discussion across, and relevant for, the influential factors. First, perspectives on *time*: to take 1 day at a time, to live in the moment, to focus on the good memories, and letting bad memories and fears for the future go. Second, perspectives on *co-activity*: to do things together, to sustain common interests, and activities of daily life. Third, perspectives on *social safety*: the degree of relational safety and closeness within the couple, and the degree of having access to safe, social and dementia-friendly arenas for interacting with other people. For couples living with dementia, knowledge about the influential factors from this narrative synthesis offers an opportunity to take control over their own relationship quality, through adopting strategies, communication patterns, and activities that may influence their relationship quality positively. To access such knowledge, however, most couples living with dementia may need information and guiding. Therefore, dementia care workers, therapists, decision-makers and researchers should take the factors described in this review into consideration when developing information and guidance material, support groups, therapeutic interventions and clinical research interventions. Dementia care services should facilitate for couples to share meaningful activities and interests, and they should offer guidance for communication strategies. Dementia-friendly communities (Mathie et al., 2022) can offer safe, local communities to prevent social isolation for couples living with dementia and thus enhance relationship quality.

### Limitations

The included studies in this review are dominated by a lack of diversity regarding gender perspectives and cultural perspectives, which is a significant limitation. All included studies exclusively describe heterosexual, binary relationships. Gender representation is quite equal in articles focusing on the healthy spouse only (8 articles both male and female, 2 articles only male, 1 article only female), but gender issues in general are very rarely discussed. The ethnic and cultural representation of participants in the included studies is also very homogenous, reflecting the researchers' nationalities: totally dominated by a western, European-American affiliation. Further research on spousal relationship quality in couples living with dementia should aim for greater gender-related diversity and cultural diversity, for a broader perspective on important influential factors.

### Conclusion

Spousal relationship quality in couples living with dementia is influenced by factors related to the dyadic perspectives within the couple, and to social and community perspectives. The couple's relationship foundation and history, their social relations, and the strategies they use in their present everyday life can contribute to an increase or decrease of relationship quality. In the development of couple-centred dementia care, the factors related to basic couplehood characteristics, communication and strategies, and activities and social life of the couple should be taken into account. Further research is needed, regarding a deeper understanding of the individual factors, a broader understanding of the relations between the factors, and cultural and gender perspectives.



## Author contributions

KS initiated and designed the study. FB and TK provided feedback on the study design. KS, FB and TK screened all titles. Abstract and full text screening, was conducted by KS, TK, KJ, and KAS. Quality appraisals were assessed by authors KS, TK, KAS, KJ, AB, and FB. The analysis was conducted by KS, with input from authors FB, TK, and H O-M through the process. KS wrote the article text drafts, authors FB and TK read, commented and contributed to revising at several time-points. Finally, all authors were responsible for commenting on drafts.

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## References

- Abdollahpour, I., Nedjat, S., & Salimi, Y. (2018). Positive aspects of caregiving and caregiver burden: A study of caregivers of patients with dementia. *Journal of Geriatric Psychiatry and Neurology*, 31(1), 34–38. DOI: [10.1177/0891988717743590](https://doi.org/10.1177/0891988717743590)
- Ablitt, A., Jones, G. V., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging & Mental Health*, 13(4), 497–511. DOI: [10.1080/13607860902774436](https://doi.org/10.1080/13607860902774436)
- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *JAMA*, 311(10), 1052–1060. DOI: [10.1001/jama.2014.304%JJAMA](https://doi.org/10.1001/jama.2014.304%JJAMA)
- Allan, M. (2018). Community music therapy to support the relationship between family carers and people living with dementia: A pilot project. *The New Zealand Journal of Music Therapy*, 16(16), 31–53.
- Alzheimer's Research UK. (2014). Care services. <https://www.dementiastatistics.org/statistics/care-services/>
- Auclair, U., Epstein, C., & Mittelman, M. (2009). Couples counseling in alzheimer's disease: Additional clinical findings from a novel intervention study. *Clinical Gerontologist*, 32(2), 130–146. DOI: [10.1080/07317110802676809](https://doi.org/10.1080/07317110802676809)
- Baker, F., Grocke, D., & Pachana, N. (2012). Connecting through music: A study of a spousal caregiver-directed music intervention designed to prolong fulfilling relationships in couples where one person has dementia. *Australian Journal of Music Therapy*, 23(23), 4–21.
- Balfour, A. (2014). Developing therapeutic couple work in dementia care – The living together with dementia project. *Psychoanalytic Psychotherapy*, 28(3), 304–320. DOI: [10.1080/02668734.2014.934524](https://doi.org/10.1080/02668734.2014.934524)
- Bauer, M. J., Maddox, M. K., Kirk, L. N., Burns, T., & Kuskowski, M. A. (2001). Progressive dementia: Personal and relational impact on caregiving wives. *American Journal of Alzheimer's Disease and Other Dementias*, 16(6), 329–334. DOI: [10.1177/153331750101600601](https://doi.org/10.1177/153331750101600601)
- Bielsten, T., Lasrado, R., Keady, J., Kullberg, A., & Hellström, I. (2018). Living life and doing things together: Collaborative research with couples where one partner has a diagnosis of dementia. *Qualitative Health Research*, 28(11), 1719–1734. DOI: [10.1177/1049732318786944](https://doi.org/10.1177/1049732318786944)
- Boss, P. (2011). *Loving someone who has dementia*. Jossey-Bass.
- Botsford, J., Clarke, C. L., & Gibb, C. E. (2012). Dementia and relationships: Experiences of partners in minority ethnic communities. *Journal of Advanced Nursing*, 68(10), 2207–2217.

- Boylstein, C., & Hayes, J. (2012). Reconstructing marital closeness while caring for a spouse with alzheimer's. *Journal of Family Issues*, 33(5), 584–612. DOI: [10.1177/0192513x11416449](https://doi.org/10.1177/0192513x11416449)
- Bruinsma, J., Peetoom, K., Millenaar, J., Köhler, S., Bakker, C., Koopmans, R., Pijnenburg, Y., Verhey, F., & de Vugt, M. (2020). The quality of the relationship perceived by spouses of people with young-onset dementia. *International Psychogeriatrics*, ■■■(■■■), 1–10. DOI: [10.1017/s1041610220000332](https://doi.org/10.1017/s1041610220000332)
- Clare, L., Nelis, S. M., Whitaker, C. J., Martyr, A., Markova, I. S., Roth, I., Woods, R. T., & Morris, R. G. (2012). Marital relationship quality in early-stage dementia: Perspectives from people with dementia and their spouses. *Alzheimer Disease and Associated Disorders*, 26(2), 148–158. DOI: [10.1097/wad.0b013e318221ba23](https://doi.org/10.1097/wad.0b013e318221ba23)
- Clark, S., Prescott, T., & Murphy, G. (2019). The lived experiences of dementia in married couple relationships. *Dementia*, 18(5), 1727–1739. DOI: [10.1177/1471301217722034](https://doi.org/10.1177/1471301217722034)
- Colquhoun, A., Moses, J., & Offord, R. (2019). Experiences of loss and relationship quality in couples living with dementia. *Dementia*, 18(6), 2158–2172. DOI: [10.1177/1471301217744597](https://doi.org/10.1177/1471301217744597)
- Conway, E. R., Watson, B., Tatangelo, G., & McCabe, M. (2018). Is it all bleak? A systematic review of factors contributing to relationship change in dementia. *International Psychogeriatrics*, 30(11), 1619–1637. DOI: [10.1017/s1041610218000303](https://doi.org/10.1017/s1041610218000303)
- Critical Appraisal Skills Programme. (2018). CASP qualitative & quantitative checklists. <https://casp-uk.net/casp-tools-checklists/>
- Daley, R. T., O'Connor, M. K., Shirk, S. D., & Beard, R. L. (2017). 'In this together' or 'Going it alone': Spousal dyad approaches to Alzheimer's. *Journal of Aging Studies*, 40(40), 57–63. DOI: [10.1016/j.jaging.2017.01.003](https://doi.org/10.1016/j.jaging.2017.01.003)
- Daniels, K. J., Lamson, A. L., & Hodgson, J. (2007). An exploration of the marital relationship and alzheimer's disease: One couple's story. *Families, Systems & Health: The Journal of Collaborative Family HealthCare*, 25(2), 162–177. DOI: [10.1037/1091-7527.25.2.162](https://doi.org/10.1037/1091-7527.25.2.162)
- Davies, H. D., Newkirk, L. A., Pitts, C. B., Coughlin, C. A., Sridhar, S. B., Zeiss, L. M., & Zeiss, A. M. (2010). The impact of dementia and mild memory impairment (MMI) on intimacy and sexuality in spousal relationships. *International Psychogeriatrics*, 22(4), 618–628. DOI: [10.1017/s1041610210000177](https://doi.org/10.1017/s1041610210000177)
- Davies, J. C. (2011). Preserving the “us identity” through marriage commitment while living with early-stage dementia. *Dementia (14713012)*, 10(2), 217–234. DOI: [10.1177/1471301211398991](https://doi.org/10.1177/1471301211398991)
- de Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., Jolles, J., & Verhey, F. R. J. (2003). Behavioural disturbances in dementia patients and quality of the marital relationship. *International Journal of Geriatric Psychiatry*, 18(2), 149–154. DOI: [10.1002/gps.807](https://doi.org/10.1002/gps.807)
- Elliott-Mainwaring, H. (2021). Exploring using NVivo software to facilitate inductive coding for thematic narrative synthesis. *British Journal of Midwifery*, 29(11), 2–6. DOI: [10.12968/bjom.2021.29.11.628](https://doi.org/10.12968/bjom.2021.29.11.628)
- Eriksen, S., Helvik, A. S., Juvet, L. K., Skovdahl, K., Førstund, L. H., & Grov, E. K. (2016). The experience of relations in persons with dementia: A systematic meta-synthesis. *Dementia and Geriatric Cognitive Disorders*, 42(5–6), 342–368. DOI: [10.1159/000452404](https://doi.org/10.1159/000452404)
- Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20(8), 423–428. DOI: [10.1111/j.1745-7599.2008.00342.x](https://doi.org/10.1111/j.1745-7599.2008.00342.x)
- Evans, D., & Lee, E. (2014). Impact of dementia on marriage: A qualitative systematic review. *Dementia (14713012)*, 13(3), 330–349. DOI: [10.1177/1471301212473882](https://doi.org/10.1177/1471301212473882)
- Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., Lyketsos, C., & Tschanz, J. (2012). Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Aging & Mental Health*, 16(6), 699–711. DOI: [10.1080/13607863.2012.678482](https://doi.org/10.1080/13607863.2012.678482)
- Feast, A., Orrell, M., Charlesworth, G., Melunsky, N., Poland, F., & Moniz-Cook, E. (2016). Behavioural and psychological symptoms in dementia and the challenges for family carers: Systematic review. *British Journal of Psychiatry*, 208(5), 429–434. DOI: [10.1192/bjp.bp.114.153684](https://doi.org/10.1192/bjp.bp.114.153684)
- Gallagher, E., & Beard, R. L. (2020). Buffer or blade: Perceived relationship closeness in couples navigating Alzheimer's. *Journal of Aging Studies*, 52, 100832. DOI: [10.1016/j.jaging.2020.100832](https://doi.org/10.1016/j.jaging.2020.100832)

- Garand, L., Dew, M. A., Urda, B., Lingler, J. H., DeKosky, S. T., & Reynolds, C. F. (2007). Marital quality in the context of mild cognitive impairment. *Western Journal of Nursing Research*, 29(8), 976–992. DOI: [10.1177/0193945907303086](https://doi.org/10.1177/0193945907303086)
- Harris, P. B. (2009). Intimacy, sexuality, and early-stage dementia: The changing marital relationship. *Alzheimer's Care Today*, 10(2), 63–80.
- Hellström, I., Nolan, M., & Lundh, U. (2005). 'We do things together': A case study of 'couplehood' in dementia. *Dementia (14713012)*, 4(1), 7–22. DOI: [10.1177/1471301205049188](https://doi.org/10.1177/1471301205049188)
- Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining 'couplehood': Spouses' strategies for living positively with dementia. *Dementia (14713012)*, 6(3), 383–409. DOI: [10.1177/1471301207081571](https://doi.org/10.1177/1471301207081571)
- Hellström, I., & Torres, S. (2021). Couplehood as a compass: Spousal perspectives on the diminished everyday competence of partners. *Dementia*, 20(7), 2380–2392. DOI: [10.1177/1471301221997306](https://doi.org/10.1177/1471301221997306)
- Hickman, H., Clarke, C., & Wolverson, E. (2018). A qualitative study of the shared experience of humour between people living with dementia and their partners. *Dementia (London)*, 19(6), 1794–1810.
- Hickman, H., Clarke, C., & Wolverson, E. (2020). A qualitative study of the shared experience of humour between people living with dementia and their partners. *Dementia*, 19(6), 1794–1810. DOI: [10.1177/1471301218805895](https://doi.org/10.1177/1471301218805895)
- Ingersoll-Dayton, B., Spencer, B., Kwak, M., Scherrer, K., Allen, R. S., & Campbell, R. (2013). The couples life story approach: A dyadic intervention for dementia. *Journal of Gerontological Social Work*, 56(3), 237–254. DOI: [10.1080/01634372.2012.758214](https://doi.org/10.1080/01634372.2012.758214)
- Kaplan, L. (2001). A couplehood typology for spouses of institutionalized persons with alzheimer's disease: Perceptions of "we"—"I". *Family Relations*, 50(1), 87–98. DOI: [10.1111/j.1741-3729.2001.00087.x](https://doi.org/10.1111/j.1741-3729.2001.00087.x)
- Kitwood, T., & Brooker, D. (2019a). *Dementia reconsidered, revisited: The person still comes first*. Open University Press.
- Kitwood, T., & Brooker, D. (2019b). *Dementia reconsidered, revisited: The person still comes first*. Open University Press.
- Mathie, E., Antony, A., Killett, A., Darlington, N., Buckner, S., Lafortune, L., Mayrhofer, A., Dickinson, A., Woodward, M., & Goodman, C. (2022). Dementia-friendly communities: The involvement of people living with dementia. *Dementia*, 21(4), 1250–1269. DOI: [10.1177/14713012211073200](https://doi.org/10.1177/14713012211073200)
- McLennon, S. M. (2008). The relationship between burden, finding meaning, and health in dementia spousal caregivers. *Southern Online Journal of Nursing Research*, 8(2), 2p.
- Merrick, K., Camic, P. M., & O'Shaughnessy, M. (2016). Couples constructing their experiences of dementia: A relational perspective. *Dementia (14713012)*, 15(1), 34–50. DOI: [10.1177/1471301213513029](https://doi.org/10.1177/1471301213513029)
- Molyneaux, V. J., Butchard, S., Simpson, J., & Murray, C. (2012). The co-construction of couplehood in dementia. *Dementia (14713012)*, 11(4), 483–502. DOI: [10.1177/1471301211421070](https://doi.org/10.1177/1471301211421070)
- Nilsson, E., & Olaison, A. (2019). What is yet to come? Couples living with dementia orienting themselves towards an uncertain future. *Qualitative Social Work*, 18(3), 475–492. DOI: [10.1177/1473325017743104](https://doi.org/10.1177/1473325017743104)
- O'Shaughnessy, M. O., Lee, K., & Lintern, T. (2010). Changes in the couple relationship in dementia care: Spouse carers' experiences. *Dementia (14713012)*, 9(2), 237–258. DOI: [10.1177/1471301209354021](https://doi.org/10.1177/1471301209354021)
- Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—A web and mobile app for systematic reviews. *Systematic Reviews*, 5(1), 210. DOI: [10.1186/s13643-016-0384-4](https://doi.org/10.1186/s13643-016-0384-4)
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hrobjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., & Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *Bmj: British Medical Journal*, 372, n71. DOI: [10.1136/bmj.n71](https://doi.org/10.1136/bmj.n71)
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *ESRC Methods Programme*, 15, 047–071.
- Power, G. A. (2016). *Dementia beyond disease: Enhancing well-being*. Health Professions Press.

- Riley, G. A., Achiampong, J., Hillberg, T., & Oyeboade, J. R. (2020). Relationship continuity and person-centred care in how spouses make sense of challenging care needs. *Aging & Mental Health*, 24(2), 242–249. DOI: [10.1080/13607863.2018.1531380](https://doi.org/10.1080/13607863.2018.1531380)
- Riley, G. A., Evans, L., & Oyeboade, J. R. (2018). Relationship continuity and emotional well-being in spouses of people with dementia. *Aging & Mental Health*, 22(3), 299–305. DOI: [10.1080/13607863.2016.1248896](https://doi.org/10.1080/13607863.2016.1248896)
- Roberto, K. A., Richter, J. M., Bottenberg, D. J., & Campbell, S. (1998). Communication patterns between caregivers and their spouses with alzheimer's disease: A case study. *Archives of Psychiatric Nursing*, 12(4), 202–208. DOI: [10.1016/s0883-9417\(98\)80025-3](https://doi.org/10.1016/s0883-9417(98)80025-3)
- Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging & Mental Health*, 9(4), 337–347. DOI: [10.1080/13607860500114555](https://doi.org/10.1080/13607860500114555)
- Sanders, S., & Power, J. (2009). Roles, responsibilities, and relationships among older husbands caring for wives with progressive dementia and other chronic conditions. *Health & Social Work*, 34(1), 41–51. DOI: [10.1093/hsw/34.1.41](https://doi.org/10.1093/hsw/34.1.41)
- Seaman, A. T. (2020). "Like He's a kid": Relationality, family caregiving, and alzheimer's disease. *Medical Anthropology*, 39(1), 29–40. DOI: [10.1080/01459740.2019.1667344](https://doi.org/10.1080/01459740.2019.1667344)
- Shavit, O., Ben-Ze'Ev, A., & Doron, I. (2019). Love between couples living with alzheimer's disease: Narratives of spouse care-givers. *Ageing & Society*, 39(3), 488–517. DOI: [10.1017/s0144686x1700109x](https://doi.org/10.1017/s0144686x1700109x)
- Sherman, C. W., & Boss, P. (2007). Spousal dementia caregiving in the context of late-life remarriage. *Dementia* (14713012), 6(2), 245–270. DOI: [10.1177/1471301207080367](https://doi.org/10.1177/1471301207080367)
- Simonelli, C., Tripodi, F., Rossi, R., Fabrizi, A., Lembo, D., Cosmi, V., & Pierleoni, L. (2008). The influence of caregiver burden on sexual intimacy and marital satisfaction in couples with an Alzheimer spouse. *International Journal of Clinical Practice*, 62(1), 47–52. DOI: [10.1111/j.1742-1241.2007.01506.x](https://doi.org/10.1111/j.1742-1241.2007.01506.x)
- Stefansdottir, O. A., Munkejord, M. C., & Sveinbjarnardottir, E. K. (2021). Maintaining or letting go of couplehood: Perspectives of older male spousal dementia caregivers. *Scandinavian Journal of Caring Sciences*, (3), 1–10. DOI: [10.1111/scs.13035](https://doi.org/10.1111/scs.13035)
- Swall, A., Williams, C., & Marmstål Hammar, L. (2020). The value of "us"-Expressions of togetherness in couples where one spouse has dementia. *International Journal of Older People Nursing*, 15(2), e12299. DOI: [10.1111/opn.12299](https://doi.org/10.1111/opn.12299)
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45. DOI: [10.1186/1471-2288-8-45](https://doi.org/10.1186/1471-2288-8-45)
- Vikström, S., Josephsson, S., Stigsdotter-Neely, A., & Nygård, L. (2008). Engagement in activities: Experiences of persons with dementia and their caregiving spouses. *Dementia*, 7(2), 251–270. DOI: [10.1177/1471301208091164](https://doi.org/10.1177/1471301208091164)
- Wadham, O., Simpson, J., Rust, J., & Murray, C. (2016). Couples' shared experiences of dementia: A meta-synthesis of the impact upon relationships and couplehood. *Aging & Mental Health*, 20(5), 463–473. DOI: [10.1080/13607863.2015.1023769](https://doi.org/10.1080/13607863.2015.1023769)
- Williams, C. L. (2015). Maintaining caring relationships in spouses affected by alzheimer's disease. *International Journal for Human Caring*, 19(3), 12–18.
- World Health Organization. (2021). Dementia. Key facts. <https://www.who.int/news-room/fact-sheets/detail/dementia>
- Wray, A. (2020). *The dynamics of dementia communication*. Oxford University Press.
- Youell, J., Callaghan, J. E. M., & Buchanan, K. (2015). 'I don't know if you want to know this': Carers' understandings of intimacy in long-term relationships when one partner has dementia. *Ageing & Society*, 36(5), 946–967. DOI: [10.1017/s0144686x15000045](https://doi.org/10.1017/s0144686x15000045)
- Hellström, I. (2014). Dignity and Couplehood in Dementia. In L. C. H. Lindemann & J. Brockmeier (Ed.), *Beyond Loss: Dementia, Identity, Personhood*, 53–66. Oxford University Press

- Searson, R., Hendry, A. M., Ramach, R. R., Burns, A., & Pur, N. (1998). Activities enjoyed by patients with dementia together with their spouses and psychological morbidity in carers. *Aging Ment Health*, 12(2), 276–282. DOI: [10.1016/s0883-9417\(98\)80025-3](https://doi.org/10.1016/s0883-9417(98)80025-3)
- Dewitte, L., Vandenbulcke, M., Schellekens, T., & Dezutter, J. (2021). Sources of well-being for older adults with and without dementia in residential care: relations to presence of meaning and life satisfaction. *Aging Ment Health*, 25(1), 170–178. DOI: <https://doi.org/10.1080/13607863.2019.1691144>

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